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AUTHOR Closs, Alison; Norris, Claire
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ABSTRACT

The duties and responsibilities of education authorities and schools in Scotland with regard to pupils who are absent for health reasons are unclear in comparison to other UK countries. This study examined in-school and out-of-school learning contexts for Scottish pupils, ages 5 through 18 years, with medical conditions of sufficient severity and duration that normal school attendance or progress might be disrupted. Data sources included surveys of Scottish education authorities, interviews with key staff, 4 detailed mainstream school studies, and 18 detailed child profiles. Findings indicated that factors influencing in-school learning included systems and levels of support for learning, schools' knowledge about and attitudes toward the medical conditions, and specific aspects of the medical condition that might incapacitate a child. Factors influencing out-of-school learning included education authorities' and schools' interpretation of their responsibilities, availability and quality of outreach services, families' and caregivers' ability and willingness to support children's education, children's motivation and capacity to learn outside school, and specific aspects of the medical condition that might incapacitate a child. Factors making positive educational outcomes more likely included good overall school ethos, nurtured partnerships between the school and others, professional development for education staff, and effective management of out-of-school education. Based on findings, it was concluded that proposed legislative changes and national guidance on the education of children with health needs will ensure that their educational needs reach a higher profile. (Includes a list of relevant organizations. Contains 12 references.) (KB)

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Alison Closs
Claire Norris

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Enabling the Education of Pupils with Medical Conditions

Alison Closs and Claire Norris

This Spotlight focuses on some of the key issues identified in an investigation into the education of children with medical conditions. The great majority of these children are registered in mainstream primary and secondary schools, whether they are present or absent. How do they get on there? How do staff and classmates cope and respond? What happens when they are absent and when they return? Are children entitled to education if they are absent from school on the grounds of health? Who is responsible for ensuring continuity and progression of these children's education? Is education of any importance to children with more serious conditions and their parents or carers? Are there any sources of 'expert knowledge' in this area?

The authors of this Spotlight address these questions and explore the way ahead, based on identified practices and on the views of children, parents, teachers and others concerned with the educational well-being of children with health needs.

In 1995 the British Paediatric Association estimated that just under 10% of children under the age of 15 have an illness 'which chronically reduces their functional capacity'. Chronic conditions – which may be alleviated but not cured by medication or other treatments – may reduce children's capacity to participate fully and regularly in education. These BPA statistics do not include children affected by acute illness, injuries or the numerous more routine and transient ills of childhood. Eiser (1993) suggests that, in all, up to 15% of the child population are affected by chronic or significant shorter term illness. These children are registered pupils present in, or sometimes absent from, our schools.

DUTIES AND RESPONSIBILITIES

Section 1 of the Education (Scotland) Act 1980 requires Education Authorities to secure 'for their area adequate and efficient provision of school education', and Section 30 requires parents either to send their children to school or to provide them with suitable education 'by other means'. However, the duties and responsibilities of education authorities and schools in Scotland towards pupils who are absent for reasons of health are, at best, unclear. Section 14 of the Education (Scotland) Act 1980 allows, but does not require, authorities to make educational provision elsewhere if children are unable to attend school.

The situation is different in the other UK countries. In England and Wales Section 19 of the Education Act 1996, as amended by section 47 of the Education Act 1997, imposes a duty on Education Authorities to provide 'suitable' education for children out of school. In Northern Ireland the same duty has been imposed through Articles 86 and 10

of the Education (NI) Orders 1998 and 1996 respectively. In England and Wales guidance to education authorities on implementing the law was also issued by the Department for Education and the Welsh Office (DfEE 1994, Welsh Office 1994). The guidance suggests that the schools in which children are registered have a part in this process, working closely with hospital and home-visiting teacher services. Guidance is awaited in Northern Ireland.

Positive moves are now afoot in Scotland with the recent publication of the report of the Riddell Committee into the education of children with severe low incidence disabilities (Scottish Executive 1999a). This report contained several recommendations about the education of children with health needs, drawing particular attention to children who might be absent from school for considerable periods of time, or recurrently for shorter periods of time, and also to the issue of medication or other medical treatment of pupils in school. The official response of the Scottish Executive to the report recognises the right of children with health needs, 'whether at home or in hospital' to the 'highest quality educational provision' (Scottish Executive 1999b). This right will be asserted through the forthcoming Improving Scottish Education Bill. Guidance to the Scottish education authorities on implementing their (probably new) duties is therefore expected early in 2000. The Scottish Executive response also promises guidance on meeting the needs for medication and medical treatment of children attending school, also addressing the concerns of involved school staff about training and legal indemnification.

Healthcare patterns are changing. The average length of hospital stay for child in-patients in the UK is now only

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two and a half days although a small minority of children may still spend months in hospital for complex surgical or medical interventions. However, for both humane and economic reasons, the emphasis now is on care in the community, ie, children are cared for, as far as possible, at home. This clearly presents a resources challenge in making out-of-school educational provision, an issue discussed later.

At a time when Scottish schools are being asked to raise all pupils' standards of performance and to ensure optimal school attendance as part of this endeavour (Quality in Education Centre 1997), it is surely worth asking about the educational experiences of pupils with substantial health problems. Although official statistics are not available, schools' experience is that absence on the grounds of health is the single largest group of absences. Pupils who are absent for significant periods of time, whether in one or two 'blocks' of time or in accumulated shorter periods, will need support for their learning.

INTRODUCTION TO THE RESEARCH STUDY

The research on which this paper is based took place between 1995 and 1997. It explored the two learning contexts, in school and out of school, of pupils registered in mainstream schools, age 5-18, with medical conditions of sufficient severity and duration that normal patterns of school attendance and/or progress might be disrupted. Illustrative conditions considered to fall within the scope of the research are: leukaemia and other cancers; ME (myalgic encephalomyelitis); AIDS/HIV; kidney and liver conditions; cystic fibrosis; ulcerative or inflamed bowel conditions; functional heart and other organ disorders; muscular dystrophy; Hurler's syndrome and other mucopolysaccharide conditions; severe asthma, skin conditions and allergic responses; glandular fever; epilepsy; extensive surgery or longer-term medical interventions.

Many of these conditions are 'unstable', with some children experiencing very variable health and others losing physical and/or mental abilities progressively. Some conditions are life-threatening while, in others, life expectancy is normal or near-normal. Many children's state of well-being and presence in school cannot be readily predicted. In order to set manageable parameters to the research, children with other very significant conditions such as mental health difficulties, head injuries, and more 'static' disabilities (such as blindness) were not included.

RESEARCH AIMS

We wanted to find out about authorities' and schools' policies and practices in the education of children with medical conditions. It was important to sample the views of children and young people themselves and of parents and teachers. If the research was to have any impact on practice we needed to know what resources were available to support those working in education so as to improve weaker aspects of provision and build on strengths.

SOURCES OF DATA

We undertook the following investigations:

- a questionnaire survey of all education authorities in Scotland (prior to the restructuring of local authorities), which produced a 100% response
- detailed interviewing of key staff (16 in all) in two demographically contrasting 'focus' authorities, including education officers/directors (1, 1), educational psychologists (2, 4), education welfare officers (0, 1), special educational needs/learning support advisers (1, 1), heads or senior teachers of specialist hospital/home teacher support services (1, 2), consultants/directors of child health services (1, 1). The numbers in brackets indicate the number of people from each category interviewed in each authority, giving totals of six for the first authority and ten for the second
- four detailed mainstream school studies (two primary and two secondary: one of each from each focus authority) - interviews with headteachers (2, 2); classteachers (1, 1), subject teachers (1, 1) and guidance teachers (1, 1); auxiliary support workers (2, 2) and school doctors (2, 2), giving totals of nine in each authority: eighteen key school staff in all. There were also extended interviews with two headteachers of special schools, both in the second authority
- eighteen detailed child profiles, all pupils in mainstream schools (two families had two affected siblings). Data for the profiles came from in-depth interviews with all sixteen mothers, and with six fathers and twelve children.

FINDINGS

► Question: What were the critical influences on children's learning?

In school the learning of children with medical conditions was found to be affected by the following:

- the systems and levels of support for learning and practical help available for all pupils and for those perceived as needing additional support
- their school's knowledge about, and attitudes towards, their condition
- specific aspects of their condition which might incapacitate or distract a child or lower their energy levels, temporarily or constantly.

Out of school learning, at home or in hospital, was influenced by the following:

- education authorities' and schools' interpretation of their responsibilities towards pupils absent on the grounds of health
- the availability and quality of outreach education services
- families' and carers' ability and willingness to support children's education
- children's own motivation and capacity to learn outside school

- specific aspects of children's condition which might incapacitate or distract them or lower their energy levels, temporarily or constantly.

► **Question: Is the common assumption that 'sick children' attract sympathetic understanding and continuing positive educational support borne out in the reality of school life?**

The quotations from our research interviews which follow illustrate clearly that there is no simple answer to the question asked. Children may have an overall positive or negative experience of education, may experience supportive, or rejecting, or non-responses from teachers and peers in school, may or may not have their healthcare needs met, may be enabled to keep up optimally with the work of classmates despite absence, or may fall hopelessly behind in work and lose all social contact.

It's a shame for him and us, we just start him on something and he seems to get hold of it, then off he goes again for another two days or three weeks, so it's one step forward and two steps back, again and again. It's all very tiresome and after a bit you lose heart and, shamefully really, stop trying. If only he could just go off, really get better, then come back and stay back.

(Year Head, of pupil with recurrent kidney condition)

Nothing was too much trouble for them, homework, sympathy, frequent enquiries.

(Guidance teacher, writing about school's response to a pupil with acute lymphoblastic leukaemia)

They are tired of him and really can't wait for him to leave school. (Same guidance teacher, writing about the same school's response to a pupil who had made a physical recovery from a brain tumour but who had residual learning and behaviour difficulties related to the condition)

Oh no, no. I really don't think we could ... I would be very unwilling ... No, they would really need to be where that could be ... I certainly would not want my staff involved in that.

(Primary school headteacher, discussing children who might need emergency medical treatment in school by injection or by rectal suppository)

They were very receptive to it, were keen to hold the Epipen and take responsibility for it which was a great comfort for us, because we'd heard, like, some horror stories of schools that banned the child which was what I was expecting and I went up there expecting a major discussion but they were actually very nice about it. ... They asked if I could get the Epipen for them and show them how to use it and that's what I did.

(Mother about school's response to using a mini-injector in emergencies for child with anaphylaxis [acute allergic] response to nuts)

It's always a bit of a thought [when a child with a serious condition is admitted or when a child already in school becomes ill]. I mean, it's not really our business, is it? Health is more for the family and medical people, but it does affect their education too, so we can't just stand by and not do anything, we have to get in there.

You know we had to do a lot of listening to the parents and the doctor, we really had to learn about the problems and then just

work out a way of coping with his health and the education. I remember thinking when David nearly died then came back to us that it would be good if we knew how another school managed. I didn't know there could be learning difficulties, I thought it was all physical. We weren't really ready for all that. Some of us [school staff] found it harder than others. Another teacher herself has a very ill child, so we've learned a lot from her. Then David and the leukaemia nurse did a great wee session with his class. There was no teasing or bullying but in some schools that could be a big issue.

(Headteacher and classteacher of child with leukaemia discussing their initial responses)

Truthfully and objectively, a mess. The individuals have been as helpful as they can be within severe limitations [of resources].

(Mother, asked to evaluate the overall education of her daughter who had been absent from secondary school for two years with ME)

The school and her friends kept in touch so well that there: really wasn't any gap to fill ... I have a great admiration for this school. They have done everything they possibly could to help us.

(Mother talking of school attended by child with cystic fibrosis who died in Primary 7)

Nobody came.

(Mother talking about lack of school response to child off school with glandular fever for nearly two terms)

What did emerge from our research, however, was a list of factors which made a positive educational outcome very much more likely. They were:

- good overall school ethos, with positive and facilitative leadership being particularly important in enabling staff and fellow pupils to respond supportively to children and families, whether children were in school or absent
- carefully nurtured partnerships between the school, support services, medical services and the family/carers and the child to ensure that healthcare and educational needs were met
- time for advance planning and review of education and flexible application of appropriate measures related to Special Educational Needs, including the development of Individualised Educational Programmes (IEPs)
- professional development for education staff to develop empathic understanding in relation to children with medical conditions
- effective management of out-of-school education.

These last two factors are now discussed in greater detail in relation to the research findings.

PROFESSIONAL DEVELOPMENT

► **Question: Why is professional development needed and what should be its focus?**

What was apparent from our interviews with education personnel at authority and school level was that most responses to questions about children with medical conditions were at a lay level, rather than at a professional

level established through policy and training. They were based on family and friendship experiences of coping with illness. For some staff this experience was minimal and they resorted to concepts derived from their own limited perspectives and stereotypes.

I wouldn't be too pleased to have my files sent home if I was off work with flu!

(Principal educational psychologist discussing his authority's ad hoc arrangements for absent pupils)

Leaman (1995) has pointed out that selection procedures for teachers still ensure that the majority come from the healthy and aspiring middle classes for whom illness, physical aspects of care and early death are not only less common familial experiences than in less socio-economically advantaged families but, when they do occur, they may also be less discussed and only covertly addressed. Some of our interviewees evidenced real discomfort in talking about children's illness, particularly when it was life-threatening or involved physical and/or cognitive deterioration. They also struggled to grasp the concept of chronic illness, the state of being neither really well nor totally incapacitated, and found it easier to think of illness and health as a dichotomy rather than as a complex continuum. This lack of understanding contributed in some cases to disbelief in the whole idea that education for absent children was needed, wanted and appreciated.

I mean, either they are well enough to come to school and get on with it, or they should be at home in bed getting well enough.

(Teacher discussing pupils who come to school when not fully functional or who need work sent home)

Some underestimated the incidence of chronic illness in the child population and did not perceive 'sick children' as coming within the range of children with special educational needs. For some personnel, the learning difficulties which generate special educational needs are still tied to physical and sensory disabilities and to cognitive impairments.

We are surely talking of only a very tiny proportion of children who would be poorly at school or absent an awful lot? Of course we need to be aware of them but they can't be very high on the logistical priority list, for instance, in comparison with children with special needs or behaviour problems who really make their presence felt in our schools.

(Education officer discussing his authority's policies and provision)

Such views persist despite the rule of thumb offered by the Scottish Office Education and Industry Department (now the Scottish Executive Education Department) in Circular 4/96 (SOEID 1996), that 'it should be assumed that children or young people have a 'learning difficulty' if additional arrangements need to be made to enable them properly to access the curriculum'. This common sense guidance widens the concept of special educational needs so that it would clearly include many children with medical conditions, thus ensuring that they came within appropriate special arrangements.

It was plain that lack of accurate information about the extent and nature of the issues, combined with lack of previous experience and relevant professional training, underlay the lack of inclusive policies and practices in relation to children with medical conditions. The long-awaited guidance from the Scottish Executive (already mentioned) will provide very necessary support to authority and school staff. However, the issue of helping those working with children with medical conditions to develop more coherent, constructive and empathic attitudes and responses will probably be best addressed by ensuring the topic is included in both initial and in-service teacher education.

Education personnel's main areas of effectiveness are in making provision, planning and delivering the curriculum, and ensuring appropriate physical and emotional contexts for learning. There would be little purpose in trying to turn teachers into paramedical professionals. What is needed is sufficient awareness-raising about the ways in which children's conditions may impact on education so that teachers and others can recognise and provide what is needed—individually flexible approaches to the curriculum and to the learning environment, along with practical involvement in required healthcare at a safe and agreed level.

While some of this awareness can come through theoretical in-puts from experienced educationalists, from the child health services and from relevant reading, the necessary staff empathy to ensure a positive educational experience for children is more difficult for education professionals to acquire. Interviewees who were already confident and experienced in working with children with medical conditions felt that relevant 'factual' learning was best prefaced by group experiential learning about interpersonal skills, involving training in active listening and person-centred approaches. Teachers and other staff could discuss and come to terms with how they felt about illness, loss and death. Without such training, staff may seem uncaring or inept, whereas they are often simply ill-prepared for the very demanding situations in which they may find themselves.

When he said he wanted to die because he was so unhappy about what the others had said but that he would be dying anyway, I didn't know what to say ... I wanted to cry or to hug him but I think I just said to get on with his work.

(Class teacher about child with a life-threatening condition who had been teased by classmates about his inability to participate in some activities)

Education staff may reject or ignore information from parents, seeing it as 'unnecessary fussing' and time-consuming. A better trained, experienced and empathic teacher would acknowledge the parent's expert knowledge of their child and would also realise the investment value of time spent listening initially. A guidance teacher described in interview how she spent 'two hours at the beginning to save twenty-two later' with parents who had concerns about their son's healthcare and education.

Two further areas of difficulty were reported:

- how to work positively with children who are losing physical and/or cognitive abilities because of the progressive nature of their condition
- the lack of understanding which may be shown to children who have conditions which appear to irritate or even repel others, notably conditions which generate discharges or cause skin eruptions, incontinence or thick coughs.

The combination of general awareness-raising, professional development in person-centred approaches, and some more detailed knowledge about how conditions affect individual children, their education and their self-esteem, might also help staff cope better with these challenges. Sharing and observing practice with other schools, including special schools, can also be effective.

I wish they had recorded his achievements more fully. Even if he wasn't able to do these things a few months later, they were real successes at the time. And it's not all losses. He had to find new ways of doing things that he could no longer do the way he had been taught at first, so there was still teaching to be done.

(Mother talking about her son who had a cognitively and physically progressive condition)

Once I was able to sit down quietly and talk with her and really listen to how she felt having to come to school like that, I really had to admire her courage and found that I was more willing to go the extra mile about homework and so on. And I could see that she was an ordinary teenager who just felt terribly hurt by what her skin did to her whole life.

(Guidance teacher of secondary pupil with acute psoriasis)

MANAGEMENT OF OUT-OF-SCHOOL EDUCATION

► **Question: Why does out-of-school education present problems and what needs to be done about it?**

Out-of-school education currently takes two main forms in Scotland: authority-based hospital or home-visiting teachers, and work supplied directly to hospital or home by the school to be carried out by the absent pupil. Sometimes – too rarely – the two forms are combined, with work from school being done at home or in hospital with outreach teachers teaching, supporting and supervising. Parents play an important supportive or even co-ordinating and delivering role in this process, particularly when children are ill at home.

Sometimes I think I am a circus ringmaster.

(Mother of child with long-term serious condition)

One of the clearest findings of the research was that, although outreach teachers themselves were often highly skilled and committed, and greatly appreciated by their pupils and pupils' families, the management of out-of-school education was ineffective at authority and school level. Even in the case of two authorities with larger combined outreach and hospital education teams, there were aspects of what debatably should be authority responsibilities which were

not properly addressed, such as inter-agency collaboration and allocation of resources. The two greatest incentives towards managing out-of-school education more effectively – in addition to enhanced professional development – will be the proposed clarification of the duties of education authorities through legislative changes and the issuing of national guidance that sets out the parameters and standards of provision.

The research identified a number of issues which contributed to the patchy and unsatisfactory nature of out-of-school education and which highlighted the benefits of schools maintaining responsibility for their absent pupils. A small sample of these is set out below.

The survey of authorities showed that most authorities did not give guidance to schools on the matter of responsibilities towards absent pupils in such matters as staying in touch and sending work home when children were fit enough to do it.

I would certainly hope that schools would send out work if parents requested it but I don't think we could require them to do this and there is no policy or circular to schools to this effect.

(Survey response from education authority officer)

If it is suspected that sick notes or phonecalls are a cover for unauthorised absence, most schools have several systems for verification – notes or phonecalls home or educational welfare officer visits. A few authorities also mentioned having notification systems involving the child health services, both in verification of illness and if they had serious worries about a child's well-being. However, there was only rarely an educational initiative from schools where a pupil had long or frequent absences on the grounds of health. Schools tended only to respond to informed and insistent parents, thereby unintentionally creating inequity in allocating scarce resources.

Schools are busy places and once a child is not there you tend to forget about them.

(Headteacher of secondary school asked about continuing links with absent pupils)

We wouldn't ... obviously, if someone was saying it was a genuine illness, we wouldn't pursue it at all. What generally happens then is that over-anxious mums or dads come and say, 'Can we have some work to keep the child busy?' Then we respond as best we can.

Headteacher of primary school asked about procedures with absent pupils)

It would be hard to get a word in in some schools about a kid whose only problem was that he was off ill for a long time.

(Educational welfare officer describing school priorities for discussion at school inter-agency liaison groups)

We have kids coming into hospital and we find they have been off [at home] for six months and nobody has done anything about it ... and the parents say, 'Well, I asked the school and they said there was nothing there'.

(Hospital teacher regretting the lack of effective publicity for outreach teaching services)

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I think I would be very worried if we weren't articulate parents. I think it would be almost impossible for a family who came from a less educated background to cope with a similar situation ... they wouldn't be able to push for home teaching perhaps and they wouldn't have the knowledge to know what to ask for. That's been very important, knowing what's available and investigating what you can do. We've been lucky that we have friends in the educational professions who've alerted us to what's available. I think it would be very difficult if you didn't have that background.

(Mother of young person absent for two years with ME)

It seemed, particularly from parent accounts, that schools 'lost track' of what work pupils missed while absent and did not pay attention to records of work accomplished out of school.

Would you believe it? They asked him what he had missed! How would he know when he wasn't there? Then when he told them what he had done at home with me and Mrs X [outreach teacher] they said he would still have to do it all again.

(Mother of secondary age pupil with lengthy and recurrent absences)

Outreach teachers were particularly depressed by what they perceived as lack of collaboration and support from schools – especially secondary schools – in this respect. They found staff very slow and unwilling to provide suggestions of work to cover and even less willing to lend books and other resources for their own pupils. This negative perception was not shared by secondary school guidance staff who felt they collaborated well, albeit in the face of resource constraints and lack of liaison time.

Outreach teachers and school staff in interview often spoke about the need for a 'broad and balanced' curriculum for all children including absentees, while at the same time stating that this simply was not possible, given the time, resources and staff currently available. Children's health also sometimes precluded intensive work. This meant that some work would be 'lost' and that children would be behind in some or all of their work when they returned to school. This was a source of very real dread to children and anxiety for parents.

I hate being behind, it makes me feel ill to think of it. I wish I didn't have to go back.

(Primary school child with frequent absences)

The reported reality was that the curriculum was not only restricted by time but also by outreach teachers' knowledge and qualifications. Some parts of the secondary curriculum could only be taught minimally and with extreme difficulty in the circumstances of hospital and most homes, the sciences and technology being particularly problematic. In other cases it was hard to find outreach teachers with the necessary curricular specialisms. The practice in some authorities of employing supply or retired teachers on an occasional basis sometimes resulted in a rather dull and uncertain diet of 'back to the basics'.

There were an awful lot of stories and pages and pages of sums. (Child reminiscing about his experience of being taught at home.)

Support on return to school was often minimal because of limited availability of support for learning, even when the child's absences and return to school were known in advance. For many children unpredictability was a feature of their condition. An acute asthmatic may be fit and well one day in school, be admitted to hospital overnight as an emergency, and then have a period of uncertain health and attendance. Schools' drive towards 'efficiency' has sometimes led managers into timetabling learning support staff fully in teaching rather than allowing them adequate time for liaison and for meeting 'unexpected' needs.

I know he needs more help when he comes back, but in our school learning support staff are fully timetabled already so we can't respond to unpredictable need.

(Principal teacher of learning support talking about pupil with frequent absences)

Some of the prevailing practices in the education of children absent on health grounds have historically logical roots. Before the advent of modern information technology it was logical for education to be entirely delivered by teachers working in hospitals or travelling to children's homes. The previous pattern of healthcare, with longer stays in hospital and brief recuperation at home before returning to school, also made this way of working sensible. Asking mothers to collect homework from the child's school made sense when either most mothers were not in employment, or when the sick child was not very sick. In many families now both parents are in employment, and when a child is ill at home, one or other parent or carer will often need to be with the child constantly, sometimes being responsible for complex medical procedures.

Authorities, schools and outreach services are now having to work more collaboratively to address the challenges of the changing situation. Some schools are trying to ensure that absent pupils do have necessary textbooks and writing materials at home, that missed work is noted and phoned home, that faxed materials are sent to the outreach teacher or, in some cases directly to the family. One Scottish authority has recently authorised the purchase of fax machines for lending to longer-term absent pupils. The internet and e-mail are making ever greater inroads into the lives of pupils and teachers at school and home. This is certainly one of the positive ways ahead which will release outreach teachers to spend more time with children who, for educational, medical or perhaps socio-economic reasons, may need a personal teacher service.

Communication established for work can also be used to maintain social contacts with their schools for absent children. We found that, although children fear falling behind in their work, they dread even more the social dislocation that absence can bring. Potential loss of friends, having to 'move down' in groupwork, changing desks, fear of being teased or bullied about any physical changes caused by the condition or treatment, or meeting new teachers, can all undermine or destroy children's wish to return to school. Teachers sometimes fear that contacting home

when children are ill could be seen as intrusive. However, we found that on-going social contact – by visit, letter, photographs, school newsletters, telephone calls – was always remarked on positively by children and parents. It seemed to play a major part in maintaining children's morale as well as in keeping pupils' interest in school work.

They'd phone every second day, just for five minutes or so. The teacher would tell her what pages to do in which books and then some of her class would chat and giggle for a bit. It was the highlight of the day.

(Mother of child whose school maintained homework and social contacts throughout frequent absences over seven years)

Even when children have life-threatening conditions, parents value education as part of the normality to which the family aspires against considerable odds, as an opportunity for achievement even if it is small and comes slowly, and as an opportunity to have some fun and to make friends or experience some level of peer company.

I know he is ill, that his life has been in the balance, but school matters to him and it matters to us, that he's having what other children have.

(Father talking about the positive educational experiences of his son who had a recurrence of leukaemia)

CONCLUSIONS

The proposed changes in legislation and the issuing of national guidance on the education of children with health needs will ensure that the educational needs of these children achieve a higher profile than before and, hopefully, a share of the additional development funds promised by the Scottish Executive – £6m per year in the next two financial years to local authorities for special educational needs. We indicated earlier that certain factors facilitated better educational outcomes for children with health needs in and out of school: positive school ethos and facilitative leadership; good collaboration with the school, medical and other services, outreach teaching services, family/carers and child; and time for advance planning and review. We then elaborated on the need for more staff development in working with children with medical conditions and on the urgency of rethinking how education out of school can be made both academically and socially effective in the changed circumstances of healthcare.

One of the most encouraging aspects of our research was that we visited schools, and heard about other schools from parents and children, where school and medical staff and families had together faced very substantial challenges successfully:

- ensuring that a child who was more absent than present throughout her entire school career never felt isolated and kept up with the main aspects of her classwork
- ensuring that two very able children were able to progress to University despite over 50% absence in their Highers years

- helping a child who was losing both mental and physical abilities to be fully part of his primary school class and recognising his achievements
- 'never once being cross with me' (child with bowel complaint and prone to 'accidents' describing her class teachers' attitudes)
- an entire school staff learning about anaphylaxis (acute allergic reaction) and how to administer a child's Epipen with all parents and children co-operating in keeping the school entirely nut-free.

Of course, not all reports were so positive, but the evidence of goodwill was widespread. Staff development for some teachers will involve them in looking at barriers within themselves about illness, physical matters and loss. None of these barriers are easy to overcome but they have enormous personal benefits for the individual him- or herself, as well as for the children with whom they work.

Rethinking outreach services will involve children's own schools with which they are registered taking an on-going overall management responsibility for their absent pupils. Many schools already try to do this, or want to do it but find themselves struggling to find the time and resources to address the work including the necessary family and outreach service liaison. Efficient record and planning systems including IEPs, already in place in very many schools, will be of enormous importance in ensuring progression for this rather unpredictable group of pupils. There will continue to be a need for a small core of trained and experienced specialist teachers who can work efficiently and empathically with individual children in the most demanding hospital, specialist provision and home conditions. They will also be important in helping mainstream school staff feel more comfortable and competent in ensuring continuity of education for the majority of children with health needs.

It would be unreasonable to expect that schools could undertake all the work necessary within existing resources. However, additional resources are no substitute for the humanity, efficiency, commitment and imagination which are also required.

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Full and abbreviated reports of the research on which this Spotlight is based (Closs, A. and Norris, C. [1997] *Outlook Uncertain: Enabling the Education of Children with Chronic and/or Deteriorating Conditions*), are available from the Department of Equity Studies and Special Education, Moray House Institute of Education, Holyrood Road, Edinburgh, EH8 8AQ, priced £12 and £6 respectively. The research was part-funded by the Scottish Office Education and Industry Department.

Useful organisations working in Scotland

Action for Sick Children is the campaigning name of the National Association for the Welfare of Children in Hospital

and is primarily concerned with medical, nursing care and general well-being of children in hospital. 15 Smith's Place, Edinburgh EH6 8NT. Tel. 0131 553 6553.

The Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) is particularly concerned about the palliative care of children with the most serious conditions and about those who provide the care, whether parents or professionals. Orchard House, Orchard Lane, Bristol, BS1 5DT. Tel. (Administration/Fax) 0117 930 4707, (Information Line) 0117 922 1556.

Children in Scotland is an umbrella organisation which is concerned with the holistic well-being of children and their rights. It liaises closely with all other children's organisations in Scotland and employs a Special Needs Development Officer. Princes House, Shandwick Place, Edinburgh EH2. Tel. 0131 228 8484.

Children's Hospice Association Scotland (CHAS), 18 Hanover Street, Edinburgh EH2. Tel. 0131 226 4933, Fax 0131 220 1626. CHAS was established to raise funds to build and support the first Scottish hospice at: Rachel House, Avenue Road, Kinross, Fife, KY13 7EP. Tel. 01577 865 777. A second hospice service is envisaged in the west of Scotland. Children's hospices aim to ensure the best quality of life and care of children with life-threatening conditions and their families.

Contact-a-Family, a voluntary organisation particularly concerned about children with medical conditions, whether inherited syndromes, impairments or illnesses. They have a special interest in families of children with rare conditions. They aim to reduce the fear and isolation of families and to develop their knowledge and empowerment. Norton Park, 57 Albion Road, Edinburgh EH7 5QY. Tel. 0131 475 2608. e-mail: Scotland@cafamilly.org.uk Internet site: www.cafamilly.org.uk

ENQUIRE, National Scottish Special Educational Needs Helpline, answers requests for information, primarily from parents/carers, about education for children with special educational needs. Tel. 0131 222 2400.

SCENT is the Sick Children's Educational Network for Teachers. E-mail: majordomo@ngfl.gov.uk

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